



Contemporary Issues in Oncology Case Management:

Genentech

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Acknowledgements

Contributors

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Program Sponsor

This program is presented on behalf of Genentech and the information presented is consistent with FDA guidelines.

Learning Objectives

1. Discuss the rationale for psychosocial assessment and intervention;
2. List common psychosocial responses to cancer diagnosis, treatment, transitions, and long-term survival;
3. Differentiate “normal” reactions from acute psychiatric/ psychological problems;
4. Apply strategies for screening and management of psychosocial issues; and
5. Discuss interventions in response to variations in cultural identity, age, developmental/intellectual

Discussion

In pairs, discuss the following:


- Think about a case you have recently managed in which there were difficult psychosocial issues.
 - What were the most difficult aspects of the case?
 - What additional resources or other factors would have made the case less difficult?

Group discussion:

- What themes are common across these experiences?
- What resources do nurse case managers need to provide psychosocial care to patients and support to each other?

Agenda

- I. Rationale for Psychosocial Intervention
- II. Psychosocial Distress and the Phases of Cancer
- III. Assessment of Special Issues and Populations
- IV. Role of the Case Manager in Psychosocial Assessment and Intervention
- V. Psychological and Psychiatric Disorders
- VI. Psychosocial Support and Treatment
- VII. Issues for the Professional Caregiver



Rationale for Psychosocial Intervention

Case Study

- Laura Smith is a 36-year-old married mother of two.
- She detected a mass in her right breast during routine self-examination and following excisional biopsy one month later, was diagnosed with ductal adenocarcinoma.
- Further workup revealed metastases to her ribs on the affected side. She is undergoing a course of chemotherapy to be followed by radiotherapy to her right breast and ribs.
- Laura and her family are insured through her employer, a local elementary school, where she is a 4th grade teacher.
- Laura's husband Jeff is self-employed as a financial planner.
- The couple's children, Noah (7) and Jamie (5), attend public elementary school 6 blocks from the Smith's suburban home.

Case Questions

- Laura relates that she “has so many worries now,” and that she doesn’t know where to turn for help.
- What are some of the likely sources of Laura’s “worry”?
- What strategies could the Case Manager use to assess the source(s) of Laura’s distress and prioritize needs/resources?

Need for Psychosocial Intervention

- Despite significant progress in prevention and treatment, cancer is still viewed by most Americans as a “death sentence.”
- The goals of cancer treatment are to extend life and to improve quality of life.
- Patients’ and families’ fears and psychological distress impact their quality of life and ability to cope with the illness, its treatment and aftermath.
- Attention to psychosocial issues reduces suffering.

Biopsychosocial Model of Cancer

Cancer is illness

- Physical aspects¹
- Short- and long-term physical and functional disability/late effects¹

Cancer is life threatening

- An existential crisis with dimensions that include the following:²
 - Psychological
 - Social
 - Biological

Cancer is chronic

1. Hewitt M, et al. Committee on Cancer Survivorship. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: National Academies Press; 2006.
2. Mental Health: Report of the Surgeon General. Accessed on July 6, 2010 at: <http://www.surgeongeneral.gov/library/mentalhealth/chapter2/sec3.html>.

Cancer Treatment and Quality of Life

- A primary goal of cancer treatment is improving QOL¹
- Meeting these goals over time requires comprehensive cancer care to:
 - Prevent secondary cancers and recurrence of cancer¹
 - Promote appropriate management to ensure the maximum number of years of healthy life¹
 - Minimize preventable pain, disability, and psychosocial distress¹
 - Support cancer survivors in accessing the resources needed to cope with their disease¹

1. Centers for Disease Control. National Action Plan for Cancer Survivorship. 2004. Accessed on 11 May 14, 2010 at: <http://www.cdc.gov/cancer/survivorship/pdf/plan.pdf>.

Incidence of Emotional Distress

- Across the different cancer types, the incidence of distress is estimated at 25% to 44%^{1,2}
- Less than 10% of patients receive psychosocial help for distress³
- Up to 58% of cancer patients in palliative care experience significant depression⁴
- Unresolved distress is associated with higher health care services utilization and cost^{5,2}

1. Zabora J, et. al. *Psycho-Oncology*. 2001;10(1):19–28.

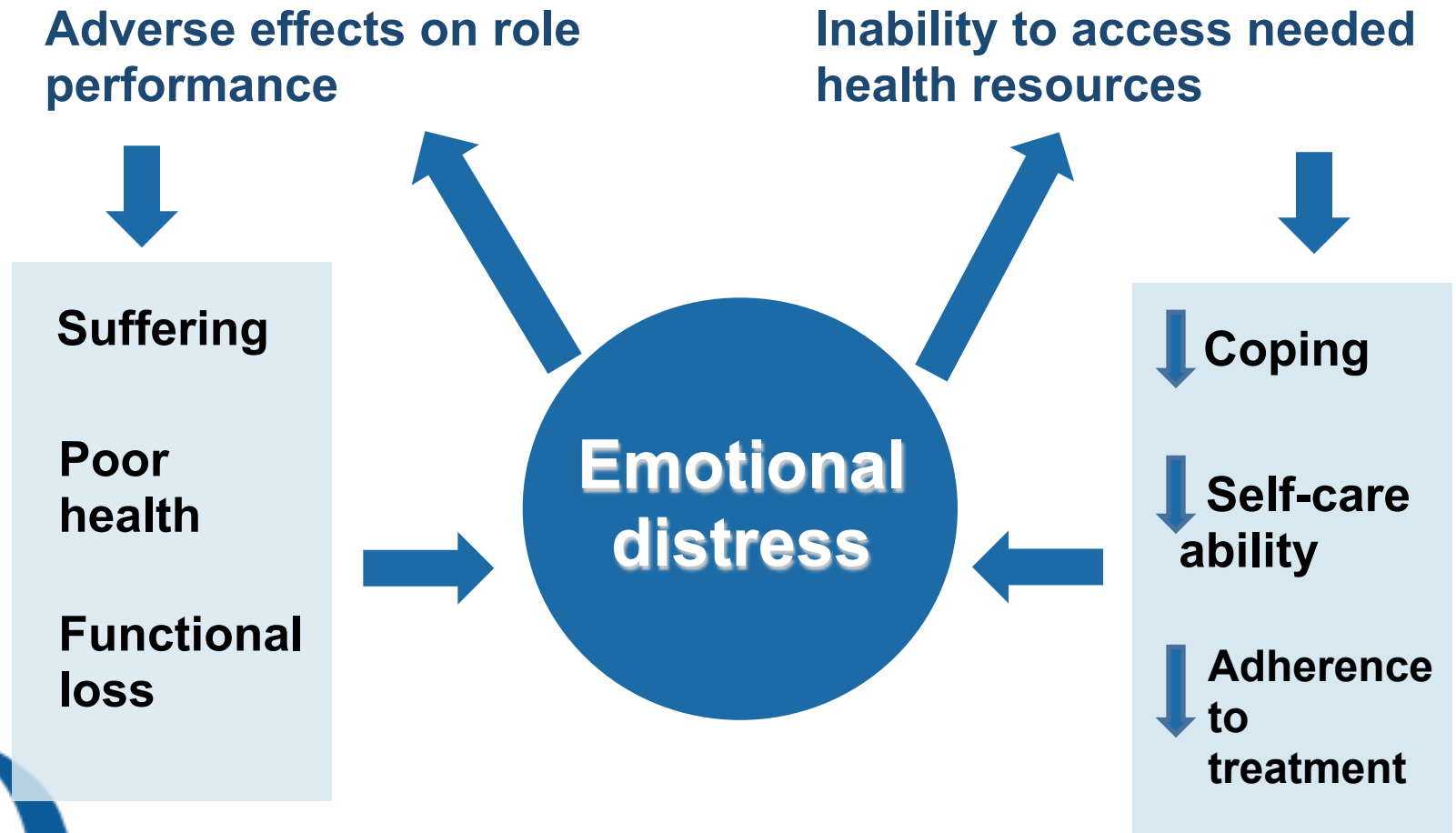
2. Carlson LE, et al. *Br J Cancer*. 2004;90(12):2297–304.

3. NCCN Practice Guidelines in Oncology, v.1.2008. Distress management. Accessed on May 17, 2010 at: http://www.nccn.org/professionals/physician_gls/PDF/distress.pdf.

4. Potash M, et. al. *Hematol Oncol Clin North Am*. 2002;16(3):671–700.

5. Bultz BD, et. al. *Psycho-Oncology*. 2006;15:93–5.

Potential Consequences of Unmet Psychosocial Needs¹



1. Institute of Medicine. *Cancer care for the whole patient: Meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. Washington, DC: The National Academies Press; 2008.

Effects of Inadequate Social Support

- Impaired coping¹
- Increased psychological distress¹
- Decreased ability to function in social roles¹
- Higher rates of depression and post-traumatic stress disorder (PTSD)¹
- Diminished ability to manage the illness experience¹

1. Institute of Medicine. *Cancer care for the whole patient: Meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. Washington, DC: The National Academies Press; 2008.

Insufficient Financial Resources

- Strong risk factor for disability, illness and death¹
- Creates barriers to purchase of food, medications, needed supplies, and access to transportation¹
 - Delay in treatment¹
 - Inability to adhere to treatment¹
 - Trade-offs – medical care sacrificed so that basic needs can be satisfied¹
 - Worse outcomes, including higher mortality¹

1. Institute of Medicine. *Cancer care for the whole patient: Meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. Washington, DC: The National Academies Press; 2008.

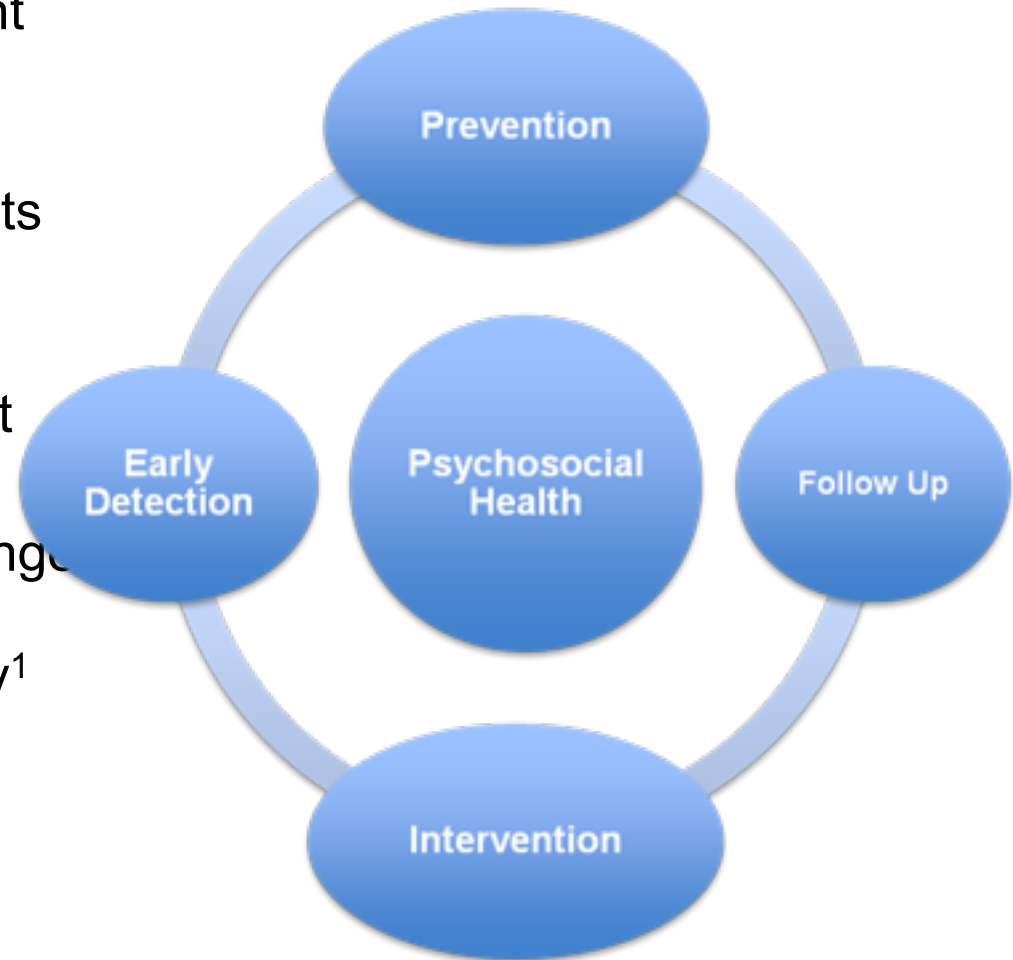
Emotional Distress and Mental Illness

- Cancer patients with pre-morbid mental illness may experience greater impairment, such as:¹
 - Lower social functioning
 - Greater disability and greater overall functional impairment
 - Impaired adherence to medical regimens and behavior changes that could improve health
 - Impaired cognition
 - Weakened motivation
 - Less effective coping

1. Institute of Medicine. *Cancer care for the whole patient: Meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. Washington, DC: The National Academies Press; 2008.

Potential Benefits of Managing Psychosocial Issues

- Improved doctor-patient communication¹
- Reduced number of physician calls and visits because of anxiety¹
- Improved patient adherence to treatment recommendations¹
- Avoidance of patient anger and development of depression and anxiety¹
- Improved QOL¹



1. NCCN Practice Guidelines in Oncology, v.1.2008. Distress management. Accessed on May 17, 2010 at: http://www.nccn.org/professionals/physician_gls/PDF/distress.pdf.



Psychosocial Distress and the Phases of Cancer

Psychosocial Distress

The term “distress” was chosen because:

- Viewed as more acceptable/less stigmatizing than:¹
 - “psychiatric”
 - “psychosocial”
 - “emotional”
- Sounds “normal” and may be less embarrassing to the patient¹
- Can be defined and measured by self-report¹

1. NCCN Practice Guidelines in Oncology, v.1.2008. Distress management. Accessed on May 17, 2010 at: http://www.nccn.org/professionals/physician_gls/PDF/distress.pdf.

Distress

- A “multi-factorial unpleasant emotional experience of a psychological, social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment”¹
- Extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis”¹

1. NCCN Practice Guidelines in Oncology, v.1.2008. Distress management. Accessed on May 17, 2010 at: http://www.nccn.org/professionals/physician_gls/PDF/distress.pdf.

Common Psychosocial Concerns

- Fear of recurrence, concerns about future and death¹
- Depression, sadness¹
- Inability to make plans¹
- Adjustment to physical compromise, health worries, sense of loss for what might have been (e.g., loss of fertility)¹
- Uncertainty and heightened sense of vulnerability¹
- Alterations in social support¹
- Fears regarding accomplishment of adult developmental tasks¹
- Existential and spiritual issues¹
- Sexuality, fertility, and intimate relationships¹
- Parenting¹
- Employment and insurance problems¹
- Relationship with the treatment team¹

1. Hewitt M, et al. Committee on Cancer Survivorship. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: National Academies Press; 2006.

Case Questions

- Laura is scheduled to begin her chemotherapy protocol next week.
- What particular concerns would you expect Laura to have at this time?
- What questions would you ask to assess psychosocial issues?

Phases of Cancer Care

- Diagnosis
- Active treatment
- Post treatment
- Long-term survival
- Recurrence
- End of life

Diagnosis Phase

Prior to diagnosis

- Normal reactions include fear, anxiety, and concern about unexplained symptoms and testing¹

At time of diagnosis

- Shock/numbness and disbelief¹
- Uncertainty and fear¹
(e.g., diagnosis, treatment, burden on family, death)
- Inability to think clearly/understand and remember information¹
- Guilt/self-blame²

1. National Cancer Institute. Adjustment to Cancer: Anxiety and Fear. Patient Version. Accessed on May 17, 2010 at: <http://www.cancer.gov/cancertopics/pdq/supportivecare/adjustment/Patient>.
2. Holland JC, et. al. *The Human Side of Cancer*. New York, NY: Harper Collins; 2000.

Diagnosis Phase

Post-diagnosis phase

- Depression/anxiety¹
- Somatic complaints, such as anorexia and sleep disorders¹
- Poor concentration¹
- Varying degrees of inability to function in daily activities¹
- Difficulty understanding and remembering information about treatment options¹
- Stresses and fears associated with awaiting treatment, particularly surgery¹

Eventually, most patients develop ways to cope, and a gradual sense of optimism about treatment is possible.¹

1. National Cancer Institute. Adjustment to Cancer: Anxiety and Fear. Patient Version. Accessed on May 17, 2010 at: <http://www.cancer.gov/cancertopics/pdq/supportivecare/adjustment/Patient>.

Cancer Treatment Phase

Fears at treatment onset

- Painful procedures¹
- Unwanted side effects (e.g., hair loss, nausea and vomiting, fatigue, pain)¹
- Interruptions to normal activities and responsibilities (e.g., work, family responsibilities)¹
- Financial impact¹

Fears during treatment

- Inability to eradicate cancer – “cure”²
- Side effects²
- Survival²

1. National Cancer Institute. Adjustment to Cancer: Anxiety and Fear. Patient Version. Accessed on May 17, 2010 at: <http://www.cancer.gov/cancertopics/pdq/supportivecare/adjustment/Patient>.

2. National Cancer Institute. Adjustment to Cancer: Anxiety and Fear. Health Professional Version. Accessed on May 17, 2010 at: <http://www.cancer.gov/cancertopics/pdq/supportivecare/adjustment/healthprofessional/allpages>.

Post Treatment Phase

Ambivalence about completion of treatment

- Sense of relief¹
- Anxiety about loss of “safety net”¹
- Fears about recurrence¹

Adjustment concerns

- Living with uncertainty¹
- Resuming previous responsibilities¹
- Hypervigilance (persistent and troubling concerns about health)¹

Coping with ongoing appointments for follow-up

- Fears of recurrence¹
- Coping with “flashback” anxiety¹

1. National Cancer Institute. Adjustment to Cancer: Anxiety and Fear. Patient Version. Accessed on May 17, 2010 at: <http://www.cancer.gov/cancertopics/pdq/supportivecare/adjustment/Patient>.

Long-Term Survival Phase

Adjustment is gradual - extending over many years

- Fear of recurrence or risk for development of new primary cancer¹
- Persistent or permanent physical effects such as fatigue, sleep disorders, sexual function, fertility¹

Poor adjustment during this phase

- Greater medical problems¹
- Lack of social support - friends and family¹
- Fewer financial resources¹
- Problems with psychological adjustment unrelated to cancer¹

1. National Cancer Institute. Adjustment to Cancer: Anxiety and Fear. Patient Version. Accessed on May 17, 2010 at: <http://www.cancer.gov/cancertopics/pdq/supportivecare/adjustment/Patient>.

Recurrence of Cancer

- Changing from cure-focused treatment goals to the goals of prolonging life and providing comfort and symptom relief can produce anxiety¹
- Resurgence of emotions from time of diagnosis including:
 - Shock, disbelief, and denial¹
 - Significant distress - depressed mood, difficulty concentrating, and frequent thoughts of death¹

1. National Cancer Institute. Adjustment to Cancer: Anxiety and Fear. Patient Version. Accessed on May 17, 2010 at: <http://www.cancer.gov/cancertopics/pdq/supportivecare/adjustment/Patient>.

Recurrence of Cancer

Normal adjustment

- Includes periods of sadness and crying, feelings of anger at God or a higher power, periods of withdrawal and isolation, and thoughts of giving up¹
- Gradual adjustment to the return of cancer occurs as expectations shift from curing to healing¹

Importance of hope

- Belief that pain and suffering can be controlled associated with hope for future QOL¹
- Security in relationships – belief that one is loved and cared for associated with hope in future relationships¹
- Religion and spirituality may help patients maintain hope¹

1. National Cancer Institute. Adjustment to Cancer: Anxiety and Fear. Patient Version. Accessed on May 17, 2010 at: <http://www.cancer.gov/cancertopics/pdq/supportivecare/adjustment/Patient>.

End of Life

Transitional adjustment

- Health care team support is essential
 - Clarify goals of care, patient/family values and preferences¹
 - Balance disease-modifying treatment goals and palliative care¹
 - Support transition to hospice¹

Psychosocial/Spiritual Considerations

- Intense grief and loss of hope²
- Fears of abandonment, isolation, suffering, death²
- Feelings of guilt and regret²
- Exhibiting anger towards family and friends²
- Development or worsening of anxiety and depression²
- Seeking meaning to one's life²

1. National Consensus Project for Quality Palliative Care (2009). Clinical practice guidelines for quality palliative care, 2nd Ed. Accessed on April 26, 2010 at: <http://www.nationalconsensusproject.org/guideline.pdf>.

2. American Cancer Society. Your Emotions and How You May Be Feeling. Accessed on May 17, 2010 at: http://ww2.cancer.org/docroot/MLT/content/MLT_5_1x_Your_Emotions_or_How_You_May_Be_Feeling.asp?sitearea=MLT.



Assessment of Special Issues and Populations

Older Adults

- Prevalence of cancer is higher among older adults than younger adults
 - Analysis of SEER data between 2003 and 2007 from found the majority of new cancer diagnoses occurred in those age 65 and older¹
 - The median age for the diagnosis of all cancers is 68 years²
- Greater need for psychosocial services for many older adults
 - Pre-existing chronic disease and associated functional impairment³
 - Greater risk for difficulty in health-related decision-making³
 - Greater risk for cognitive losses³
 - Potential for lack of social supports/ pre-existing isolation³

1. National Cancer Institute. Annual Report to the Nation on the Status of Cancer 1973-1999. Accessed on May 18, 2010 at: <http://www.cancer.gov/newscenter/1999-annual-report-age-burden-QA>.
2. National Cancer Institute. Seer Cancer Statistics Review 1975-2007. Accessed on May 18, 2010 at: http://seer.cancer.gov/csr/1975_2007/results_merged/topic_age_dist.pdf.
3. Ershler WB. *J Support Oncol*. 2003;1(suppl 2):5-10.

Cultural Factors

Key Assessment Domains ¹	Questions ¹
Family Roles/Decision Making	Who makes the decisions in your family? (Do we need to bring this person into the telephone conversation?)
Disclosure of Information	What important customs should we know about? What do you want your family to know/ not to know? Is your treatment team aware of these preferences?
Language	What is your native language? (To assess understanding of medical terminology, e.g., “When I say the word “chemotherapy,” what does that mean to you?) Would you prefer to have written materials in (your native) language?
Perception of Illness	Have you or a family member ever been ill or hospitalized before? What was that like? What worries you the most about your/your family member’s illness?

1. Kagawa-Singer, et al. *JAMA*. 2001;286:2993-3001.

Familial Risk

- Familial-related cancers
 - Often diagnosed at a younger age¹
 - Frequently more aggressive, with the development of multiple tumors in one or more organs¹
- Patients have additional fears and worries about development of cancer in other family members (e.g., offspring)¹

1. National Cancer Institute. Cancer Genetics Overview. Accessed on May 18, 2010 at: <http://www.cancer.gov/cancertopics/pdq/genetics/overview/healthprofessional>.

Familial Risk

Addressing Psychosocial Concerns through Genetic Counseling *Indications for counseling*

- Strong family history of cancer¹
- Multiple affected relatives; some at an atypically early age (varies by cancer type) ¹

Benefits

- Links patient to skilled practitioners who can realistically address patient's concerns^{1,2}
- Provides evaluation of genetic risk and risk management plan^{1,2}
- Supports coping strategies for patient and family members^{1,2}

Risks

- Emotional distress²
- Stressful impact on choices – medical, social (e.g., marriage, child bearing)²

1. National Cancer Institute. Cancer Genetics Risk Assessment and Counseling. Accessed on May 18, 2010 at: <http://www.cancer.gov/cancertopics/pdq/genetics/risk-assessment-and-counseling/healthprofessional/allpages>
2. National Cancer Institute. Cancer Genetics Overview. Accessed on May 18, 2010 at: <http://www.cancer.gov/cancertopics/pdq/genetics/overview/healthprofessional>.

Sexuality Assessment

- Sexuality - includes all the feelings and actions associated with loving someone, not just the act of sex^{1,2}
- Patients may feel uncomfortable broaching this topic^{1,2}
- Encourage the patient to speak to her/his treatment team²
- Patient-focused resources:
 - American Cancer Society (www.cancer.org)
 - Sexuality for Women and their Partners
 - Sexuality for Men and their Partners

1. Mick JM. *Clin J Oncol Nurs*. 2007; 11(5):671-75.

2. American Cancer Society. Sexuality. Accessed on May 18, 2010 at: http://www.cancer.org/docroot/MBC/content/MBC_2_3x_Sexuality.asp?sitearea=MBC.

Assessing Concerns About Sexuality

“BETTER” Model

- **B**ring up the topic.¹
- **E**xplain that you are concerned with quality-of-life issues, including sexuality. Although you may not be able to answer all questions, convey that patients can talk about any concerns they have.¹
- **T**ell patients that you will help to find appropriate resources to address their concerns.¹
- **T**iming might not seem appropriate now, but acknowledge that patients can ask for information at any time.¹
- **E**ducate patients about the side effects of cancer treatments.¹
- **R**ecord your assessment and interventions in patients' medical records.¹

1

1. Mick JM. *Clin J Oncol Nurs*. 2007;11(5):671-75.

Case Questions

- In your experience, how might problems related to intimacy, sexuality and fertility manifest in a patient like Laura?
- How might you respond to such concerns?



Role of the Case Manager in Psychosocial Assessment

Psychosocial Health Services

- “...are psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness and its consequences to promote better health.”¹

1. Institute of Medicine. *Cancer care for the whole patient: meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. Washington, DC: The National Academies Press; 2008.

A Framework for Action: IOM Recommendations

- All cancer care should ensure the provision of appropriate psychosocial services by:
 - Facilitation of effective patient-provider communication¹
 - Identification of each patient's psychosocial needs¹
 - Design and implementation of patient-specific care plans¹
 - Systematic re-evaluation and care plan updates¹

1. Institute of Medicine. *Cancer care for the whole patient: Meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. Washington, DC: The National Academies Press; 2008.

Role of the Case Manager

- Case Manager plays a critical role in assessing the need for, coordinating, and evaluating patient response to psychosocial health services and interventions¹
- Case Managers perform the following activities:¹
 - Coordination of care
 - Development of individualized care plans for at-risk individuals
 - Support adherence to medical treatment plans
 - Facilitation of referrals for needed services
 - Monitoring outcomes, including cost-effectiveness
 - Impartial advocacy for plan members
 - Initial and ongoing education

1. Mullahy C. *The Case Manager's Handbook* (3rd Ed.). Sudbury, MA: Jones and Bartlett Publishers; 2004.

The Imperative: Screening for Psychosocial Needs Across the Continuum of Cancer Care

- Case managers should not rely on patients to volunteer their needs¹
- CMs should actively elicit patient needs and refer for services/support
 - Asking about psychosocial needs during structured or unstructured interviews¹
 - Screening of patients using validated instruments:
 - Distress Thermometer and Problem List (NCCN): Visual analog scale and 35-item problem list²
 - Psychosocial Screen for Cancer (PSSCAN) – 21 item tool¹
 - Screening should occur at the initial visit, at appropriate intervals, and when clinically indicated, particularly when a change in disease states occurs (e.g., remission, recurrence, progression)²

1. Nancy E. Adler, Ann E. K. Cancer Care for the whole patient: Meeting psychosocial health needs. Institute of Medicine. 2008.
2. NCCN Practice Guidelines in Oncology, v.1.2008. Distress management. Accessed on May 17, 2010 at: http://www.nccn.org/professionals/physician_gls/PDF/distress.pdf.



Psychological and Psychiatric Disorders

Adjustment Disorder

Definition¹

- Behavior or mood more extreme than expected in reaction to a cancer diagnosis, treatment, recurrence or side effects
- Symptoms may include anxiety, sadness, sleep and appetite disturbances, problems in functioning with family, friends, and at work

Progression¹

- Usually begins within three months of the first signs of distress
- Typically resolves over time
- Can progress to chronic adjustment disorder or anxiety disorder

1. National Cancer Institute. Adjustment to Cancer: Anxiety and Fear. Health Professional Version. Accessed on May 17, 2010 at: <http://www.cancer.gov/cancertopics/pdq/supportivecare/adjustment/healthprofessional/allpages>.

Anxiety Disorder

*Psychological symptoms may include:*¹

- Worry, apprehension, fear, sadness, ruminations

Physical symptoms may include:^{1,2}

- Tachycardia, shortness of breath, tremor, diaphoresis, nausea, xerostomia, insomnia, dizziness, difficulty swallowing

*Patterns of anxiety*³

- Intermittent, in response to stressor (e.g., appointments)
- Persistent and pervasive
- Panic attack with paroxysmal acute anxiety

1. National Cancer Institute. Adjustment to Cancer: Anxiety and Fear. Health Professional Version. Accessed on May 17, 2010 at: <http://www.cancer.gov/cancertopics/pdq/supportivecare/adjustment/healthprofessional/allpages>.
2. National Institutes of Mental Health. Generalized Anxiety Disorders. Accessed on May 4, 2010 at: <http://www.nimh.nih.gov/health/publications/anxiety-disorders/generalized-anxiety-disorder-gad.shtml>.
3. Holland JC, et al (eds.). *Quick reference for oncology clinicians: the psychiatric and psychological dimensions of cancer symptom management*. 2006.

Anxiety Screening Questions¹

- Do you feel shaky, jittery, or nervous?
- Have you felt tense, fearful, or apprehensive?
- Have you had to avoid certain places or activities because of fear?
- Have you felt your heart pounding or racing?
- Have you had trouble catching your breath when nervous?
- Have you had any unjustified sweating or trembling?
- Have you felt a knot in your stomach?
- Have you felt like you have a lump in your throat?

1. National Cancer Institute. Anxiety Disorders. Accessed on May 19, 2010 at: <http://www.cancer.gov/cancertopics/pdq/supportivecare/anxiety/healthprofessional/allpages>.

Major Depressive Disorder (MDD)

Accurate diagnosis is difficult

- Transient sadness and mood changes in response to cancer are both expected and normal¹
- Standard for assessment and diagnosis is clinical interview²
- Single-item screening questions may be useful (i.e., “Are you depressed?”)³

Symptoms may include¹:

- Depressed mood
- Diminished pleasure or interest in most activities
- Significant weight loss/gain or decrease in appetite
- Insomnia or hypersomnia, fatigue or loss of energy
- Feelings of worthlessness or excessive, inappropriate guilt
- Diminished ability to think or concentrate
- Recurrent thoughts of death or suicide

1. National Cancer Institute. Depression. Accessed on May 19, 2010 at: <http://www.cancer.gov/cancertopics/pdq/supportivecare/depression/HealthProfessional>.
2. Agency for Healthcare Research and Quality. Management of Cancer Symptoms: Pain, Depression, and Fatigue. Summary, Evidence Report/Technology Assessment: Number 61. AHRQ Publication No. 02-E031, July 2002 Accessed on May 19, 2010 at: <http://archive.ahrq.gov/clinic/epcsums/cansympsum.pdf>.
3. Chochinov HM, et al. *Am J Psychiatry*. 1997; 154:674–76. Accessed on May 3, 2010 at: <http://ajp.psychiatryonline.org/cgi/reprint/154/5/674>.

Assessing Suicidal Risk

Risk factors

- Gender
 - Males more likely than women to commit suicide after diagnosis¹
- Cancer type
 - Lung, bladder, head and neck, esophagus and myeloma and patients with metastatic disease¹

Warning signs

- Communication of a plan and sense of imminence²
- Access to means – e.g., pill stockpiling, guns²

Be aware of your health plan suicide prevention protocol

1. Kendall WS. *Ann Oncol.* 2007;18:381-87.

2. National Cancer Institute. Depression. Accessed on May 19, 2010 at: <http://www.cancer.gov/cancertopics/pdq/supportivecare/depression/HealthProfessional>.

Sleep Disorders

Symptoms¹

- Insomnia, difficulty falling asleep or staying asleep and waking up earlier than desired

Causes¹

- Depression ,anxiety, pain, breathing problems, medication side effects

Self-management¹

- Treat any underlying physical condition that disturbs sleep (e.g., pain, breathing difficulties)
- Sleep hygiene practices

1. Claman D. Sleep Disorders and Management. Accessed on May 20, 2010 at: http://www.cancersupportivecare.com/sleep_disorders.html.

Case Question

- Laura has been receiving chemotherapy for the past three months. When you ask her how she is feeling, she tells you that she is feeling “okay physically, a little tired” but cries at least once most days. In response to your query about her husband, she reports that he has been very helpful with the children, but he seems distant. She says that she knows this is hard on him too, but they don’t seem to be able to talk about her illness.
- What additional assessment is indicated?
- Are Laura’s emotions within the range of “normal”? Why or why not?



Psychosocial Support and Treatment

Section Overview

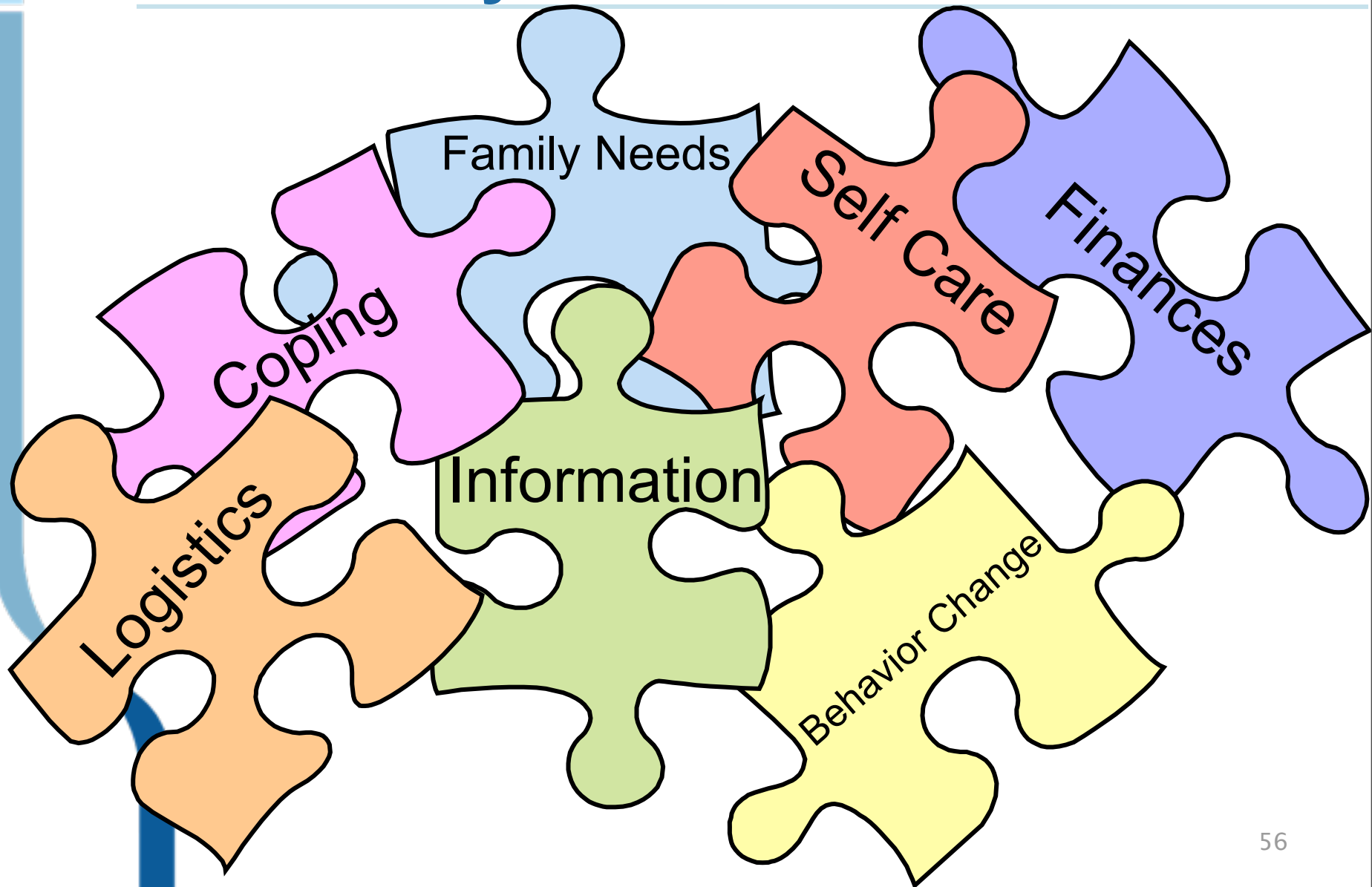
- Psychosocial Problems and Services
- Social Support
- Psychological Interventions
- Supportive Psychotherapy
- Cognitive Behavioral Interventions
- Information Needs
- Practical Matters and Logistics
- Self-Help Strategies
- Complementary Therapies
- Palliative Care
- Resources

Effectiveness of Psychosocial Interventions

- In general, patients are highly satisfied with psychosocial interventions¹
- Group therapy, education, structured and unstructured counseling, and cognitive behavioral therapy offered the most promise for their medium- and long-term benefits¹

1. Newell SA, et. al. *J Natl Cancer Inst.* 2002;94(8):558–84.

The Challenge: Assembling the Necessary Pieces



Psychosocial Health Services

Psychosocial	Types of Health Services ¹
Need for information about illness, treatment, health and services	<ul style="list-style-type: none"> • Self-help sources for information – e.g., ACS, NCI, The Wellness Community, Cancer type-specific resources • Assistance to understand and apply the information
Coping with emotions	<ul style="list-style-type: none"> • Peer support (e.g., ACS local units, “I Can Cope” programs; National Coalition for Cancer Survivors) • Counseling/psychotherapy to individuals or groups • Psychopharmacology – following comprehensive assessment and in a context where follow-up and monitoring is provided
Need for help to manage illness	<ul style="list-style-type: none"> • Illness management and self-care programs (e.g., OncoLink, CancerCare have disease-specific guidance online)

1. Institute of Medicine. *Cancer care for the whole patient: meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. Washington, DC: The National Academies Press; 2008.

Psychosocial Health Services

Psychosocial	Types of Health Services ¹
Need for assistance changing behaviors to minimize disease impact	<ul style="list-style-type: none">• Behavioral/health promotion interventions available through the patient's cancer care provider• Peer support (ACS, The Wellness Community, CancerCare)
Inadequate material and logistical resources	<ul style="list-style-type: none">• Transportation and other logistics – local ACS unit (“Road to Recovery”); LIVESTRONG™ SurvivorCare partnership between CancerCare and the Lance Armstrong Foundation; Local Area Agencies on Aging, “NeedyMeds” assistance with locating financial assistance for medication costs
Difficulty managing or inability to manage disruptions in work, school and family life	<ul style="list-style-type: none">• Family and caregiver education (ACS, etc.), assistance with ADLs (local community organizations, visiting nurses), legal protection and assistance (NCCS)

1. Institute of Medicine. *Cancer care for the whole patient: meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. Washington, DC: The National Academies Press; 2008.

Psychosocial Health Services

Psychosocial	Types of Health Services ¹
Financial advice and/or assistance	<ul style="list-style-type: none">• Financial planning/counseling including management of day-to-day activities such as bill paying (e.g., Patient Advocate Foundation, NCCS)• Insurance counseling (e.g., Patient Advocate Foundation, NCCS)• Eligibility assessment and counseling for other benefits (Social Security Administration)• Supplemental financial grants (Government Benefits.gov; PAF)

1. Institute of Medicine. *Cancer care for the whole patient: meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. Washington, DC: The National Academies Press; 2008.

Social Support

- Defined: “A network of family, friends, neighbors, and community members that is available in times of need to give psychological, physical, and financial help.”¹
- Plays a central role in self-management of illness and can improve health outcomes²

1. National Cancer Institute. Dictionary of Cancer Terms: Social Support. Accessed on May 20, 2010 at: http://www.cancer.gov/Templates/db_alpha.aspx?CdrID=440116.
2. Institute of Medicine. *Cancer care for the whole patient: meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. Washington, DC: The National Academies Press; 2008.

Types of Social Support

Emotional support

- Caring behaviors and expressions that facilitate effective individual coping¹
- Listening, empathizing, reassuring¹

Informational support

- Increases knowledge and may lead to more effective health care utilization¹
- Education, guidance, advice¹

Instrumental support

- Material or logistic assistance that may help individuals to act on new knowledge¹
- Transportation, financial support, personal care, household chore assistance¹

1. Institute of Medicine. *Cancer care for the whole patient: meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. Washington, DC: The National Academies Press; 2008.

Informal or Peer Support Groups

Benefits

- Information sharing¹
- New or strengthened coping skills¹
- Reduced isolation¹

Types

- In-person such as:¹
 - Diagnosis-specific, (e.g., breast cancer or prostate cancer)
 - Age-specific, (e.g., teens or young adults)
 - Patient-only and family-only vs. mixed
- Online¹

1. Institute of Medicine. *Cancer care for the whole patient: meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. Washington, DC: The National Academies Press; 2008.

Psychological Interventions

- Supportive psychotherapy
- Family and couples therapy
- Cognitive behavioral interventions

Supportive Psychotherapy

- Provision of emotional support and encouragement for adaptive coping¹
- Has been demonstrated to produce the following:¹
 - Reduce anxiety and depression
 - Improve QOL and well-being

1. Institute of Medicine. *Cancer care for the whole patient: meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. Washington, DC: The National Academies Press; 2008.

Cognitive Behavioral Therapy

- Based on the premise that behavior change can be facilitated by introducing and reinforcing new learning¹
- Evidence of effectiveness for psychological and physical symptoms in cancer patients^{2,3}
- Interventions include the following:³
 - Problem solving skills
 - Relaxation training
 - Guided imagery
 - Reframing thoughts

1. Hazlett-Stevens H, et al. Brief Cognitive-Behavioral Therapy: Definition and Scientific Foundations. In: Bond F, Dryden W, ed. *Handbook of Brief Cognitive-Behavioral Therapy*. 2002.
2. Antoni MH, et al. *Am J of Psychiatry*. 2006;163:1791–797.
3. Institute of Medicine. *Cancer care for the whole patient: meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. 2008

Psychopharmacotherapy in Cancer Care

- Use of psychotropic drugs to reduce anxiety, depression, and other psychiatric symptoms that are pre-existing or develop during cancer treatment¹
- Multiple clinical trials have found psychotropic drugs are effective in preventing and relieving depression and anxiety in cancer patients¹
- Use of drug therapy in cancer patients is recommended in national and international clinical guidelines^{2,3}
- Choice of psychotropic agent is dependent on medical history, comorbid diseases, symptomology, previous responses to medications, and side effect profiles⁴

1. Institute of Medicine. *Cancer care for the whole patient: meeting psychosocial health needs*. Nancy E. Adler and Ann E. K. Page, eds. 2008.
2. National Breast Cancer Centre and National Cancer Control Initiative. 2003. Clinical practice guidelines for the psychological care of adults with cancer. Accessed on May 20, 2010 at: http://www.nhmrc.gov.au/_files_nhmrc/file/publications/synopses/cp90.pdf.
3. NCCN Practice Guidelines in Oncology, v.1.2008. Distress management. Accessed on May 17, 2010 at: http://www.nccn.org/professionals/physician_gls/PDF/distress.pdf.
4. National Cancer Institute. Depression. Accessed on May 19, 2010 at: <http://www.cancer.gov/cancertopics/pdq/supportivecare/depression/HealthProfessional>.

Information Needs

- Patients and their families express needs for a wide range of information¹
- Variety of strategies are effective
 - Literature review found that healthcare professionals, medical pamphlets, and family/friends are the most commonly used information sources for cancer patients¹
 - Mass media sources including magazines, television, radio, and Web sites are additional information sources¹
 - Most patients obtain information from more than one or two sources¹

1. Ankem K. *Information Research*. 2006;11(3):paper 254. Accessed on May 21, 2010 at: <http://www.informationr.net/ir/11-3/paper254.html>.

Research on Information Needs

- The following information is perceived to be the most important to cancer patients:¹
 - 1) spread of the disease
 - 2) likelihood of cure
 - 3) treatment options
 - 4) side effects of treatment
 - 5) effect on family and friends
 - 6) risk of disease to family
 - 7) impact on work, daily activities, and social life
 - 8) self-care issues
 - 9) sexual concerns

1. Degner LF, et al. *JAMA*. 1997;277:1485-92.

Case Questions

- Case Managers have an important role in fulfilling patients' and families' health education and emotional support needs.
- How can the nurse case manager distinguish between social support needs – namely, emotional, informational and instrumental?
- What are the critical steps in matching information resources to information needs?

Managing Practical Matters

- Review insurance policies to determine coverage and limits¹
- Record all disease and treatment-related expenses¹
- File insurance claim forms promptly¹
- Maintain files with copies of all records¹
- Track bill payment and seek assistance with payment schedule if needed¹
- Draft will, living will, durable power of attorney¹

1. Thiboldeaux K, et. al. *The Total Cancer Wellness Guide*. Dallas, TX: BenBella Books; 2007.

Improving Communication with HCP

The following methods can advance understanding and memory of communications with a HCP:1

- Ask a family member or friend to go with you.
- Take notes during the visit.
- Visualize what is being explained to you.
- Ask for explanations in terms familiar to you.
- Ask how you can learn more.
- Rephrase your question and/or the doctor's answer.
- Verbalize what you heard. Repeat to the doctor what you thought he or she said.
- Take a small recording device with you.

1. Clark EJ, ed. *Teamwork: The cancer patient's guide to talking with your doctor*. Silver Springs, MD: National Coalition for Cancer Survivorship;2006.

Self-Help Strategies for the Newly Diagnosed

1. Acknowledge the change that cancer has brought to one's life¹
 - Express the range of emotions
2. Become informed¹
 - Gather information or designate someone else to fulfill this role (e.g., family member, friend)
3. Get organized¹
 - Organize information about the disease and treatment, medical records
 - Assign someone to be the “go-to” person to provide updates to friends/ family
 - Choose someone to assist with organizing the practical aspects of daily life (childcare, household chores, meals)

1. Thiboldeaux K, et. al. *The Total Cancer Wellness Guide*. Dallas, TX: BenBella Books; 2007.

Self-Help Strategies for the Newly Diagnosed

Partner with the healthcare team^{1,2}

- Seek help to deal with “distress” and feelings of hopelessness

Don't blame oneself^{1,2}

- Guilt about causing one's illness can lead to other self-defeating reactions
- Fears about inability to sustain a “positive attitude” interfere with coping

Use laughter as medicine^{1,2}

- Balance the difficulties of a new reality with those activities that bring joy

1. Thiboldeaux K, et. al. *The Total Cancer Wellness Guide*. Dallas, TX: BenBella Books; 2007.
2. Holland JC, et. al. *The Human Side of Cancer*. New York, NY: Harper Collins; 2000.

Complementary Therapies

- Used in conjunction with standard cancer treatments¹
- Mind-body therapies including:¹
 - Yoga/stretching
 - Biofeedback and hypnosis
 - Imagery and meditation
- Biologically-based therapies including:¹
 - Vitamins and herbs
 - Special foods/diets
- Manipulative and body-based practices including:¹
 - Massage
 - Reflexology
- Energy medicine including:¹
 - Tai Chi
 - Therapeutic touch

1. National Cancer Institute. Thinking about Complimentary and Alternative Medicine. Accessed on May 21, 2010 at: <http://www.cancer.gov/cancertopics/thinking-about-CAM/allpages>.

What is Palliative Care?

- Palliative care is both a philosophy and a system for delivering care¹
- The goals of palliative care are as follows:¹
 - Prevent and relieve suffering
 - Optimize functioning
 - Support decision making
 - Support quality of life for patients and their families
- Palliative care can be delivered concurrently with life-prolonging care or as the main focus of care¹

1. National Consensus Project for Quality Palliative Care (2009). Clinical practice guidelines for quality palliative care, 2nd Ed. Accessed on April 26, 2010 at: <http://www.nationalconsensusproject.org/guideline.pdf>.

Palliative Care/Hospice Care in Context

Palliative Care

- An approach to care that emphasizes choice, control, and comfort at any point on an illness trajectory¹
- Reimbursement is a standard fee for reimbursable provider services
- Interdisciplinary care that addresses patient/family's physical, psychosocial, spiritual and financial needs¹

Hospice Care

- An approach to care at the end of life (last 6 months) that emphasizes choice, control and comfort¹
- Reimbursed under the Medicare program and subject to Medicare regulations¹
- Interdisciplinary care that addresses patient/family's physical, psychosocial, spiritual and financial needs¹

1. National Caregivers Library. Hospice vs. Palliative Care. Accessed on May 5, 2010 at: <http://www.caregiverslibrary.org/Default.aspx?tabid=375>.

Cancer Support Organizations

- American Cancer Society
- National Coalition for Cancer Survivorship
- CancerCare
- The Wellness Community
- Lance Armstrong Foundation
- Cancer Supportive Care Programs
- NCI Resources

Case Question

- Laura has completed her chemotherapy and has begun radiation therapy. She returned to work for a few months while she was receiving chemotherapy, but is now extremely fatigued and able to go to work just 1-2 days/ week. She is worried about finances and is having difficulty getting the children to school, even though it is just 6 blocks from their home. She has lost 15 pounds. When you ask her about Jeff, she tells you that she and Jeff have been sleeping in separate bedrooms because she is restless at night and gets up frequently.
- What assessment is needed? What services might



Issues for the Professional Caregiver

Compassion Fatigue 1

- What is compassion fatigue (CF)?
 - Case managers, like all nurses, are at risk for exhaustion of their capacity for empathy¹
 - CF is a stress response that causes a decline in the caregiver's ability to experience joy or care for others¹
- What are the effects of CF?
 - Diminished job performance^{1,2}
 - Reduced personal satisfaction^{1,2}
 - Compromised family role^{1,2}
 - Decreased physical well-being^{1,2}

1. McMullen L. Oncology nursing and compassion fatigue [abstract]. Oncology Nursing Society Conference. 2007. Accessed on May 21, 2010 at: <http://www.nursinglibrary.org/Portal/main.aspx?pageid=4024&pid=18507>.
2. Luquette J. Stress, compassion and burnout: effective self-care techniques for oncology nurses [abstract]. Oncology Nursing Society Conference. 2007. Accessed on May 21, 2010 at: <http://www.nursinglibrary.org/Portal/main.aspx?pageid=4024&pid=18488>.

Compassion Fatigue 2

What are some self-care techniques to address CF?

- Cognitive behavioral¹
 - Individual: distancing/detaching via guided imagery/relaxation, assertiveness training, establishing boundaries¹
 - Group: debriefing, grief support¹
- Existential - finding meaning in life and suffering¹
 - Prayer, personal reflection, meditation, and restoring a life balance¹

1. Luquette J. Stress, compassion and burnout: effective self-care techniques for oncology nurses [abstract]. Oncology Nursing Society Conference. 2007. Accessed on May 21, 2010 at: <http://www.nursinglibrary.org/Portal/main.aspx?pageid=4024&pid=18488>.

Moral Distress

- Nurses' perceptions about "futile" care may create significant distress...why?
 - Nurses are frequently in the "center" between patients and other health care providers¹
 - Perception that futile care interferes with patient access to necessary palliative care¹
- Interventions for moral distress
 - Education on identifying and diagnosing moral distress²
 - Interventional programs targeted to nurses at high risk²
 - Interdisciplinary forums to discuss cases of moral distress²
 - Nursing participation on an institution's ethics committee²
 - Open access to discuss cases/situations with ethics committee²

1. Ferrell BR. *Oncology Nursing Forum*. 2006; 33(5):922-30.

2. Pendry PS. *Nurs Econ*. 2007;25(4):217-21. Accessed on May 21, 2010 at: <http://www.medscape.com/viewarticle/562718>.

Summary

- Psychosocial needs often remain undetected unless directly assessed, and can dramatically affect patients' and families' quality of life.
- Case managers have the opportunity to screen patients for psychosocial needs across the continuum of cancer care.
- There are resources available to assist patients with cancer and their families.



Appendix



Cancer Support Organizations

American Cancer Society

<http://www.cancer.org/>

- Online and local, office-based resources for health care professionals and patients/families friends
- Extensive patient/family information
 - Learning about cancer
 - Preparing for treatment
 - Coping with treatment
 - After treatment
- Useful patient tools
 - Calendar, email groups, bookmarks, to-do lists
- Community-based programs
 - (e.g., I Can Cope, Reach to Recovery, Road to Recovery, Look

National Coalition for Cancer Survivorship

<http://www.canceradvocacy.org/>

- The oldest survivor-led cancer advocacy organization in the country
 - advocating for quality cancer care for all Americans and
 - empowering cancer survivors
- Evidence-based advocacy for systemic changes at the federal level in how the nation researches, regulates, finances, and delivers quality cancer care.
- Organizes Cancer Advocacy Now!™, a legislative advocacy network that engages constituents across the country in federal cancer-related issues.
- Patient education resources include the Cancer Survival Toolbox® and “A Cancer Survivor’s Almanac.”

CancerCare

<http://www.cancercare.org>

- Not for Profit organization that provides free professional support services
 - Counseling
 - Education
 - Financial assistance
 - Practical help
- Services provided by trained oncology social workers

Contact Information

CancerCare National Office
275 Seventh Avenue
New York, NY 10001

Email: info@cancercare.org

Services Telephone:

- 212-712-8400
- 1-800-813-HOPE (4673)

The Wellness Community/Cancer Support Community

<http://www.thewellnesscommunity.org/>

- Founded in 1982 by Dr. Harold Benjamin
- International non-profit organization that provides free support, education and hope to people with cancer and their loved ones.
 - Goals: Regain control, reduce isolation and restore hope regardless of the stage of disease
 - Services: Professionally-led support groups, educational workshops, nutrition and exercise programs, and stress-reduction classes
- More than 100 locations worldwide including 24 U.S.-based and 2 international centers with 73 satellite and offsite programs and online at The Virtual Wellness Community.
- Unified with Gilda's Club Worldwide in 2010 to form Cancer Support Community

Cancer Supportive Care Programs

<http://www.cancersupportivecare.com/>

- Established in 1999 at the Center for Integrative Medicine at Stanford University Medical Center
- Goals:
 - Reduce the morbidity and toxicity of the disease and cancer therapy, and improve the general physical and mental health.
 - Improve the quality of life for newly diagnosed cancer patients on therapy, as well as promote long-term survivorship.
 - Expand currently available supportive care modalities that will include reviews of screening, detection, diagnosis, treatment, as well as complementary programs for knowledge about comorbidities with mind-body, nutrition, exercise, sexuality, and general supportive care website modules for cancer-specific problems.
 - Provide information on promotion of better health and improved survival through diet, exercise and supportive care recommendations.

NCI Resources (Useful Fact Sheets)

<http://www.cancer.gov/cancertopics/factsheet/Support>

Advance Directives - A fact sheet that explains informed consent and end-of-life issues during advanced or terminal disease.

Palliative Care in Cancer - A fact sheet that describes the role of palliative care, which is comfort care given to a patient who has a serious or life-threatening disease, such as cancer, from the time of diagnosis and throughout the course of illness. This fact sheet discusses the difference between palliative care and hospice care, how to locate palliative care, who pays for this type of care, and where to find information about research on this topic.

End-of-Life Care: Questions and Answers - This fact sheet answers some of the questions that many patients, their family members, and caregivers have about the end of life.

Financial Assistance and Other Resources for People With Cancer - A fact sheet that lists organizations that can help patients and their families with

NCI Resources (Useful Fact Sheets)

<http://www.cancer.gov/cancertopics/factsheet/Support>

Hospice - A fact sheet about organizations that provide hospice care; it also discusses insurance coverage.

How To Find Resources in Your Own Community If You Have Cancer - A fact sheet that discusses the types of help that are available to people with cancer and where to find these services.

More Choices in Cancer Care: Information for Beneficiaries on Medicare Coverage of Cancer Clinical Trials - A fact sheet about Medicare coverage of clinical trials for cancer treatment; it includes resources for more information about clinical trials and Medicare benefits.

National Organizations That Offer Services to People With Cancer and Their Families - Organizations that provide cancer patients and their families with financial and emotional support, advocacy, and information may be found by searching this database.

[NCI's Patient Navigator Research Program: Fact Sheet](#) - A fact sheet about



Thank you!